Care needs of people with dementia in Tanzania and associated impact on carers: A cross-sectional, observational study

Introduction

The global prevalence of dementia is around 57.4 million, which is projected to rise to 152 million by 2050. This is in part due to population growth and ageing, with the increase most marked countries undergoing demographic transition, such as those in sub-Saharan Africa (SSA) (Nichols et al., 2022). The global costs of dementia consisting of direct medical care, social care and informal care are high. The proportion of costs relating to informal care is highest in SSA, accounting for 75.6% of costs compared to 37.6% in western Europe (Prince et al., 2015).

The United Republic of Tanzania is a lower middle-income country located in East Africa. The age-standardised prevalence of dementia in Tanzania is estimated to be similar to high income countries (HICs) (Longdon et al., 2013), with an age-adjusted prevalence of 8.9% in over 70s in the Kilimanjaro region (Yoseph et al., 2021). However, there is currently no health policy for dementia services or treatment in Tanzania (Ministry of Health, 2017). Barriers to healthcare for older people in Tanzania include a lack of healthcare professionals trained in understanding their needs and a lack of specific services (Ministry of Health, 2017). There is currently poor awareness of dementia in Tanzania and, whilst symptoms of dementia are recognised, they are often viewed as part of normal ageing, or believed to be a form of spiritual punishment (Hindley et al., 2017). Carers may not report symptoms of dementia due to stigma surrounding the disease, and tend to only present when there are significant behavioural issues. This leads to a very low diagnostic rate, which is a barrier to improving dementia care (Mushi et al., 2014).

Dementia dramatically impacts the quality of life (QoL) of the person with the condition as well as their families and informal carers . Caring for a person living with dementia involves a significant expenditure of time, energy and money which intensifies as the condition progresses (Schulz & Martire, 2004). In SSA, the carers burden may go unrecorded and is likely to be higher compared to HICs due to low dementia awareness and limited formal support (Dotchin et al., 2014). It is common for younger female family members to take on a caregiving role, as carer burden increases, allowing males to continue to work (Paddick, Kisoli, et al., 2015). A recent systematic review of the caregiving experience of people living with dementia found that most considered caregiving as a family responsibility in keeping with cultural norms (Mwendwa et al., 2022). A study showed that carers in Nigeria spent more time assisting the person with dementia with activities of daily living (ADLs) (median=9 hours/day) compared to India, South Asia and China (median=3 hours/day) (Prince et al., 2004). This may be due to poor physical environment with few adaptations to support those with

disability in Nigeria, compared to other low and middle-income countries (LMICs) (Dotchin et al., 2014).

Previous research in LMICs found the following associations with increased carer burden: being a female carer; greater time spent assisting with ADLs; behavioural and psychological symptoms of dementia; and cutting back on work in order to care (Paddick, Kisoli, et al., 2015; Prince et al., 2012). Previous studies have included little or no data from SSA, and there is very limited data from Tanzania. One study in Tanzania found that 47.3% of carers of people with dementia declined to complete carer burden assessments, as they believed the care they provided was not above what was culturally expected of them (Paddick, Kisoli, et al., 2015). It has also been suggested that traditional multi-generational households do not provide protection against carer burden. However, carer burden may be shared amongst multiple family members residing in multi-generational living arrangements (Prince et al., 2012).

This study aims to explore:

1. The care arrangements, and care needs, of people with mild-to-moderate dementia aged over 60 presenting to the outpatient department of a regional hospital in Tanzania
2. The level of carer burden in this group
3. Associations between level of carer burden and characteristics of people with dementia and their carers

Methodology Study design

This was a cross-sectional, observational study. Ethical approval granted by National Institute for Medical Research in Dar-es-Salaam and by local ethics committee within Kilimanjaro Clinical Research College, number 2245. We used data from the CST-International study, which aimed to implement Cognitive Simulation Therapy (CST) in Tanzania, a group therapy for people with dementia, which improves quality of life and cognition (Spector et al., 2019). The broader CST-International study has four phases to the implementation research study; (i) exploration of barriers to implementation via interviews, (ii) development of implementation plans for each country, (iii) evaluation of implementation plans measuring outcomes, (iv) refinement and dissemination of implementation strategies. The research presented here is part of phase III of CST implementation.

Eligibility

All outpatients aged over 60 presenting to a regional hospital were invited to take part in cognitive screening. Patients who consented to the study were and screened for dementia using the Identification Intervention for Dementia in Elderly Africans (IDEA) cognitive screen (Gray et al., 2014). This tool was developed and validated in a community-based elderly population in rural

Tanzania and aims to minimise educational and literacy bias compared to other cognitive screening tools. It contains six questions testing all areas of cognition affected by dementia, and has a scoring range of 0-15. Completion of consent forms and screening was conducted by the local research team made up of clinical psychologist and junior doctor.

Participants with an IDEA cognitive screen score of ≤9 were invited to take part in a further assessment for dementia (a score of ≤7 suggests probable dementia, and 8-9 suggests possible dementia) (Paddick, Gray, et al., 2015). This assessment was carried out by a junior doctor trained in dementia diagnosis using DSM-IV criteria. The level of dementia severity was judged by the research team and a score of 5-8 indicating mild dementia and a score of 1-4 indicated moderate dementia. Participants who were diagnosed with dementia were invited to take part in CST groups. Baseline assessments were carried out with the people with dementia who agreed to participate, and their carers (see data collection).

The primary aim of the screening was to identify participants with mild-to-moderate dementia to take part in CST groups. Those with a medical illness deemed too severe to be able to take part in CST groups, as judged by the researcher, were excluded from screening.

Recruitment

Participants with dementia and their carers were recruited from the outpatient department at a regional hospital in Tanzania between 22nd October 2018 and 20th April 2019. Participants were identified through the outpatient department register, those over 60 attending for a medical condition other than dementia were invited to take part. As part of the larger CST study the aim was to recruit 50 CST participants thus sampling ended once this threshold was reached. This was calculated pragmatically based on time and resources of the team. Participants who were deemed too unwell by the recruitment team were excluded and those unwilling to consent. The study aims were explained verbally, and informed consent was obtained from the person with dementia and their carer. Participants either signed consent forms, or gave a thumbprint if they could not write. If a person with dementia was deemed to lack capacity to consent, written assent was obtained from their carer.

Data collection

All data collection was undertaken in Swahili in the outpatient department of the regional hospital. Details of each assessment were recorded on paper and subsequently anonymised and entered into a database. Demographic variables were collected from the person with dementia and their carers including age, gender, education level, literacy status, marital status and living situation. If age was unknown a method that uses historical events to estimate age was used, which has been previously validated in SSA (Paraïso et al., 2010). As participants presented to the same hospital, urban location

was determined by those living within 10 kilometres of the city centre. The following measure was administered to the person with dementia:

- **The World Health Organisation Abbreviated Quality of Life Questionnaire (WHO-QoL BREF)** was used to measure self-rated QoL. It is a self-reported 26-item questionnaire centred around four domains; physical health, psychological health, social relationships and the environment, and is a reliable cross-culturally valid assessment of QoL (Skevington et al., 2004). The question on sex life satisfaction was omitted due to cultural reasons, so the scale consisted of 25 questions.

The following measures were administered to the carer of the person with dementia:

- **The Zarit Burden Interview (ZBI)** was used to measure carer burden. ZBI is a 22-item questionnaire with a scoring range of 0-88. Studies report strong construct validity and high correlation with other carer burden measurement tools (Seng et al., 2010).

- **Identification and Intervention for Dementia in Elderly Africans - Instrumental Activities of Daily Living (IDEA-IADL)** measures IADLs, which are complex tasks first affected in cognitive impairment, before ADLs (Lawton & Brody, 1969). IDEA-IADL is an 11-item proxy-rated screen with a scoring range of 0-44, where higher scores indicate more impaired functioning. It was developed and validated in Tanzania and has high construct validity (Collingwood et al., 2014).

- **Client Services Receipt Inventory (CSRI)** (Personal Social Services Research Unit, n.d.) and **Resource Use in Dementia (RUD)** (Wimo et al., 2013) include a structured interview with carers to measure the person with dementia's ADL care needs. It included yes/no questions on whether the person with dementia was able to feed, bathe, dress and communicate independently.

Data analysis

Demographic and clinical data were analysed descriptively. We used bivariate analyses to explore differences in carer burden according to characteristics of carers and people with dementia, including sex, age, carer occupation, relationship to person with dementia, carer education, IDEA cognitive screening score and IDEA-IADL score. These explanatory variables were chosen based on a priori selection. ZBI score was the dependent variable. Suggested cut off scores for ZBI are 0-21, little or no burden; 21-40, mild to moderate burden; 41-60, moderate to severe burden; 61-88, severe burden (Bédard et al., 2001). Due to small numbers in each category, scores were dichotomised into low (0-40) and high (41-88). Mann-Whitney U tests were used for independent variables with two groups,

and Kruskal-Wallis *H* tests for independent variables with three or more groups. Non-parametric tests were chosen, as due to the small sample size we were unable to assume normality.

We then explored independent associations between variables using multivariable logistic analyses. Variables that produced a bivariate p-value of ≤0.1 were entered into a multivariable logistic regression model, with ZBI score as the dependent variable. We then carried out backward elimination, using the likelihood ratio function. SPSS software was used for all analyses.

Results

Demographics

A total of 2463 patients were approached for screening, of which 1389 consented, and 248 were excluded due to severe medical illness. Of the 1141 assessed for dementia, 57 participants were diagnosed with dementia, with 53 people with dementia and their carers were consenting to take part in the study (Figure

Figure 1: A consort diagram showing recruitment to the study
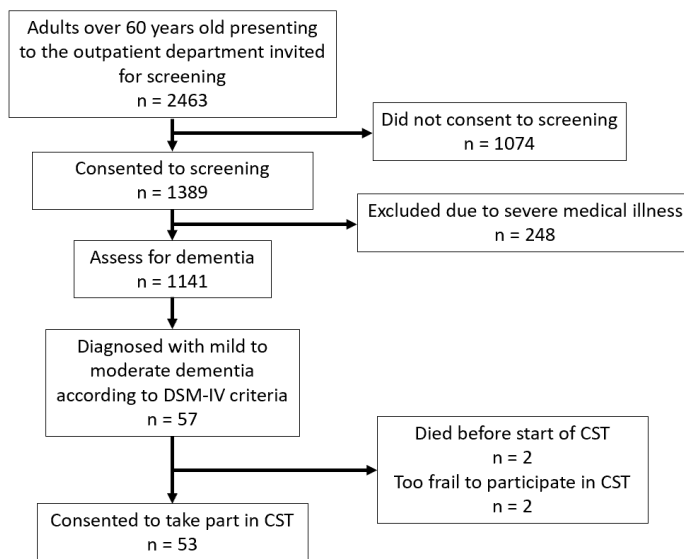
The mean age of the person with dementia was 77.8 years (SD = 10.05). As shown in Table 1, the majority of people with dementia were female (n=36, 68%), living in an urban area (n=39, 74%) and married (n=42, 97%). Seven people with dementia (13%) had never attended school yet almost all (n = 50, 94%) were able to read and write. The mean age of carers was 45.5 years (range 30-67 years).

Most carers were female (n=36, 68%), daughters of the person with (n=23, 43%) and married (n=51, 96%). Further sociodemographic characteristics of carers are shown in Table 1, most carers worked with many working in the informal sector in farming (n=14, 26%) or running market stalls (n=29, 55%).

Care arrangements

All carers had other dependents; 51 (96%) had children to look after and 2 (4%) had other adults to care for. Forty-five (85%) of the carers interviewed, self-reported doing more than 60% of the caring. Additionally, almost all had help from others for the caregiving (n=51, 96%). Eighteen (34%) carers had additional help from two others whilst seven carers (13%) reported having additional help from four or more others. Nine (17%) carers reported that they had paid help during the day, with eight (15%) having regular help and one (2%) having only occasional help. No carers had paid help overnight.

Care needs

The mean IDEA-IADL score was 38.04 out of 44 (SD = 5.778), showing considerably high dependency. More than 90% of carers reporting that the person with dementia either needed lots of help with, or was unable to do, all the tasks asked within the IDEA-IADL questionnaire. Most people with dementia (n=35, 66%) were unable to uphold justice within their community and 32 (62%) were unable to delegate responsibility. Additionally, 27 (52%) people with dementia were unable to look after grandchildren.

The majority of people with dementia (n=36, 68%) could still feed themselves. Nearly half of people with dementia (n=23, 43%) could not take care of themselves in the bathroom and 47 people with dementia (89%) could not select the right clothes to wear. Many carers reported that the person with dementia had difficulty communicating, with 49 (93%) having word finding difficulties. Only 10 people with dementia (19%) were able to obtain the correct change and 43 (81%) had difficulty handling money.

Carer burden

The median ZBI score was 46 out of 88(IQR = 11). Thirty-eight (72%) carers were experiencing moderate to severe burden, scoring between 41 and 60. Only one (2%) carer had little to no burden and one (2%) had severe burden. The ZBI questionnaire showed that high proportions of carers nearly always felt that their relative asks for more help than needed (n=29, 56%).

Table 1: Sociodemographic and clinical characteristics of sample

Variable	Total (N=53)
Characteristics of person with dementia	
Age (years), mean (SD)	77.8 years (10.05)
Sex	
Female	36 (68%)
Male	17 (32%)
Location	
Urban (living within 10 kilometres of city centre)	39 (74%)
Rural	14 (26)
Marital status	
Married	42 (79%)
Widowed	11 (21%)
Education level	
None	7 (13%)
Lower primary (1-4 years)	36 (68%)
Higher primary (5-7 years)	3 (6%)
Higher education	7 (13%)
Literacy	
Able to read and write	50 (94%)
Not able to read and write	3 (6%)
Living with family members	53 (100%)
Cognitive (IDEA score, range 0-15), median (IQR)	3 (2)
Activities of daily living (IDEA-IADL score, range 0-44), mean (SD)	38.04 (5.78).
WHO-QoL BREF total score	64.38 (3.14)
Physical health sub score	2.35 (0.71)
Psychological health sub score	2.12 (0.39)
Social relationships sub score	3.92 (0.44)
Environment sub score	2.75 (0.96)
Self-rated QoL	
Poor or very poor	15 (28%)
Neither	29 (55%)
Good	9 (17%)
Characteristics of carers	
Age (years), mean (SD)	45.5 years (16.75)
Sex	
Female	36 (68%)
Male	17 (32%)
Relationship to person with dementia	
Wife	7 (13%)
Daughter	23 (43%)
Son	12 (23%)
Daughter-in-law	1 (2%)
Brother	1 (2%)
Granddaughter	4 (8%)
Grandson	4 (8%)
Neighbour	1 (2%)
Employment	
Salaried/professional	5 (9%)
Not salaried	45 (85%)
Not working	3(6%)
Other dependents	
Child dependents	51 (96%)
Adult dependents	2 (4%)
Additional carers providing help	
0	2 (4%)
1	15 (28%)
2	18 (34%)
3	11 (21%)
4+	7 (13%)
Receiving paid help during the day	9 (17%)
Carer burden – ZBI score (possible range 0-88), median (IQR)	46 (11)

Associations with carer burden

Unadjusted analyses showed that carer burden differed according to sex and self-rated QoL of the person with dementia, with female carers and those caring for someone with a worse self-rated QoL experiencing higher carer burden as highlighted in bold in Table 2.

The following variables were below the threshold of $p \leq 0.1$ and were entered into the multivariable model: sex of carer, sex of person with dementia, age of person with dementia, IDEA cognitive screen total score and QoL rated by the person with dementia. The multivariable results indicate evidence of an independent association between being a female carer and experiencing higher carer burden, with an odds ratio of 3.68 (95% CI=1.04-12.99, p=0.043).

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Table 2: Bivariate analysis exploring carer burden according to characteristics of people with dementia and carers

		Low-moderate burden (n =14)		Moderate-high burden (n=39)		Mean difference (M-W / K-W tests)	
		Median	IQR	Median	IQR	U / H *	p-value
Carer sex	**Male**	**35**	**17**	**47**	**4.5**	**198.00**	**0.039**
	Female	**33.5**	**10**	**49**	**7**		
Carer age	≤ 45	35	14	50	6.5	398.00	0.391
	> 45	38	10	46	5.5		
Carer work status	Salaried/professional	24	13	52	7.5	127.00	0.815
	Not salaried	35	13	47	6.25		
Relationship to person with dementia **	Same generation	33.5	6.5	46	9	0.27*	0.873
	Adult child generation	32.5	12.5	50	6.5		
	Grandchild generation	40	0	45.5	1.75		
Carer education	None-minimal	36.5	6.25	48	5.5	366.50	0.644
	Completed primary-further education	27	10.5	47	8.25		
Additional carers	0-1	27	13.5	46	7	2.21*	0.331
	2	35	11.75	50	6		
	≥ 3	35	7.5	49	7.25		
Sex of person with dementia	Male	35	14	46.5	3.5	218.50	218.5
	Female	35	10.5	50	7		
Age of person with dementia	≤ 77	35	3	49	7.25	244.00	0.062
	> 77	30	13	46	5		
IDEA cognitive screen score	≤ 2	40	2.5	51	5.5	4.61*	0.098
	3	28.5	9.75	46	4.75		
	≥ 4	37	9	47	7		
IDEA-IADL score	≤ 40	32.5	10.75	47	8	336.00	0.693
	> 40	37.5	11	50	5		
Person with dementia's self-rated QoL	**Poor or very poor**	**37**	**2.5**	**51.5**	**8.25**	**8.13***	**0.017**
	Neither	**38**	**11.5**	**46.5**	**5.75**		
	Good	25	9	47	1		
Duration of symptoms	≤ 3 years	36	11	47	7	343.00	0.251
	> 3 years	36.5	10.75	50	5.5		
ADL – Person with dementia is able to feed themselves	Yes	37	10	47	6	302.50	0.814
	No	27	13	50.5	6.75		
ADL – Person with dementia can take care of themselves in bathroom	Yes	36	10.25	47	4.75	364.50	0.726
	No	32.5	12.5	53	8		

ADL = Activities of daily living; IDEA-IADL = Intervention for Dementia in Elderly Africans Instrumental Activities of Daily Living; QoL = Quality of life; SD = Standard deviation. *Kruskal-Wallis H tests for independent variables with three or more groups. **1 carer with high burden who was not related to the person with dementia was excluded from this category.

Discussion

This is the first studyspecifically investigating the care needs, care arrangements and carer burden of people with dementia and their carers in Tanzania. There have been a few previous studies of people with dementia in SSA but with different primary aims (Dotchin et al., 2014; Paddick, Kisoli, et al., 2015). Further studies have been conducted across LMICs yet these have often excluded SSA, or contain a small cohort from SSA, therefore this study significantly increases knowledge on caregiving for people with dementia in SSA (Prince et al., 2004, 2012).

Care needs

The care needs of our cohort were high, especially IADL care needs that were measured using a culturally appropriate and locally developed tool (Collingwood et al., 2014). Over 90% of people with dementia were unable to carry out, or required lots of help, in all IADL tasks. IADL function is affected before ADL function in cognitive impairment. Because our cohort had mild-to-moderate dementia, IADLs would be affected first (Lawton & Brody, 1969). Previous studies have not distinguished between care needs of ADL and IADL, which may have resulted in an underestimation of care needs.

Carer burden

The median ZBI score was 46 out of 88, with higher scores indicating greater burden. It is possible that this is an underestimate, as the carers who are the frailest or experiencing the highest burden are likely less able to attend outpatients.

However, the score is higher than studies carried out in LMICs by the 10/66 Dementia Research Group (Prince et al., 2004, 2012). A 2004 study found a similarly high mean ZBI score of 50.3 in Nigeria (Prince et al., 2004) . Caregiving for someone with dementia in SSA compared to other LMICs may be more burdensome, due to a lack of formal support and cultural differences leading to a higher burden. Additionally, a systematic review of the caregiving experience of people living with dementia in SSA (Mwendwa et al., 2022) found that the financial strain of caring was the largest contributor to burden. This may also be influenced by the level of development of the healthcare system and government support.

A contributing factor to the difference on levels of carer burden may be due to the validity of the ZBI in SSA, despite it being the most widely used measure of carer burden (Ankri et al., 2005). It has been previously used in SSA, but not formally validated. There are concerns that the ZBI may not be culturally valid in cultures that have great respect for their elders (Prince et al., 2004). Further research is required to explore if the higher level of burden experienced in Nigeria and Tanzania is replicated elsewhere, and if burden is higher in SSA than in other LMICs. There is a considerable time difference since these studies in 2012 and 2004, and care arrangements, habits and practices,

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may have changed significantly since these studies, so there is a need for a repeat multi-site study which includes more countries from SSA.

Gender

We found that young, female family members of people with dementia were more likely to be the main carers. Despite support from others within a multi-generational household, these carers reported still providing the majority of the care. Our results are similar to a previous study conducted in Tanzania (14) in that most carers are female (68% in our study vs. 84.6% in previous study) and children or children-in-law (68% in our study vs. 66.7% in previous study). Results from studies in multiple LMICs found that the main carer was usually female (59-95%) and most carers lived with the people with dementia (55-98%) (Prince et al., 2004), in contrast to HICs where there is greater access to paid carers. Our results also suggest that carers are supported by family or friend networks to care for people with dementia. However, 85% of carers interviewed still reported doing 60% or more of the caregiving.

We found that being a female carer was significantly and independently associated with higher carer burden, which is similar to previous studies in LMICs (Prince et al., 2012). This could be due to traditional gender roles in SSA, meaning that females are more likely to take on the caregiving role as the person with dementia's function declines (Paddick et al., 2015).

Limitations

The sample includes only individuals who attended the outpatient department for another medical condition and were subsequently screened for and diagnosed with dementia on enrolment to the study. This should be considered when interpreting the results, as the sample may differ from the wider population in Tanzania. For example, they may have a higher socio-economic status, as they were able to attend the hospital in the first place. However, we were limited by the lack of caseload of people with dementia to recruit from in the absence of a routine screening in a memory clinic structure or diagnostic programme for dementia.

The small sample size increases the risk of a type 2 error, so future studies should include a larger sample size in order to increase the validity of the results. Furthermore, future studies should include different locations within the country to increase the generalisability of results.

Only those with mild-to-moderate dementia were included in this study, thus no individuals with severe dementia were included. Those deemed too frail to participate in CST were also excluded. Therefore, our findings are not representative of those with more severe dementia or other comorbidities. This study only recruited participants presenting to hospital with symptoms not related to dementia, this may exclude a proportion of proportion of patients with dementia who might be unwilling to attend hospital due to the stigma of their symptoms.

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Conclusion

This is the first study in Tanzania investigating care needs, care arrangements and carer burden for people with dementia. Very high IADL care needs were identified along with high carer burden. This highlights the need for a sustainable low-resource carer intervention to reduce carer burden which would improve both outcomes and QoL for people with dementia and their carers. Furthermore, higher levels of carer burden were in line with those found previously in SSA, which were higher than in other LMICs. Future research into differences in carer burden between LMICs would improve understanding. Further development of culturally valid and reliable tools to assess carer burden in SSA is also required.